A Comprehensive Approach for Developing a Rapid Tissue Donation Program

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CONFLICTS OF INTEREST

• I, or an immediate family member, including my spouse or partner, have NO financial relationship(s) relevant to the content of this educational activity.
LEARNING OBJECTIVES

• Describe at least one benefit of rapid autopsy or rapid tissue donation.

• Recognize at least one barrier for recruiting cancer patients to a rapid tissue donation program.

• Identify at least three recommendations on ethical guidelines to recruit patients to a rapid tissue donation program.

Rapid Tissue Donation

• Rapid tissue donation (RTD) is a novel method of tissue procurement in which tissue is collected within 24 hours following the death of a patient.

• The goals of RTD programs are to obtain high quantity and quality tumor tissue from both the primary tumor and metastasis.

• These tissues provide tremendous cancer research possibilities and hope for new treatments.
Background

- While the use of RTD offers many opportunities to develop new therapies, it raises ethical concerns.
- There are limited RTD trainings or protocols for biomedical researchers or health care professionals regarding the ethical aspects of the request for tissue donation.

Study Supplement Aims

- **Aim 1.** Conduct formative qualitative research to explore the knowledge, perceptions, and potential barriers of recruiting lung SPORE patients for an RTD program at Moffitt Cancer Center.
  - Surveyed HCPs
  - Conducted focus groups with patients and HCPs
  - Conducted semi-structured interviews with community stakeholders
Moffitt Survey

Assessing knowledge and perceptions of Moffitt physicians and advance practice professionals for RTD (N=91: 60% MD; 32% ARNP/PA; 3% DO/PhD)

• Knowledge:
  • 66% never heard of RTD; 78% rated knowledge as none/limited

• Practice:
  • 30% report patients ask about donating body to science
  • 93% never had experience recruiting patients for ethically sensitive program.

• Attitudes:
  • 71% worry about the emotional state of patients following introduction of RTD

Focus Group Recruitment

We want to hear your opinion!

If you are:
* A thoracic patient or primary caregiver of a thoracic patient at Moffitt Cancer Center
* Over 18 years old
* Capable of speaking and reading standard English
* Willing to participate in a telephone focus group and provide informed consent

Join us for a telephone focus group to discuss your opinion about Rapid Tissue Donation (RTD)

The purpose of this research study is to explore the knowledge, perceptions, and potential barriers of recruiting participants for rapid tissue donation at Moffitt Cancer Center.

You will be compensated for your time with a $25 Gift Card

If you are interested please call us at 813-745-6102 or E-mail us at LATTE@moffitt.org

We will ask you of the following to see if you are eligible to participate in this research study:

• 1.23 MOFFITT CANCER CENTER & RESEARCH INSTITUTE - A NOETR COMPREHENSIVE CANCER CENTER - TAMPA, FL
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Focus Groups

Assessing knowledge and perceptions of cancer patients/survivors, (n=17); caregivers (n=6); physicians (n=6) and clinic staff (n=9) from the Thoracic department at Moffitt Cancer Center.

- Majority had low knowledge of RTD
- All groups perceived advancement of science as a benefit to the program
- Majority agreed physicians should have initial RTD discussion, but only with patients who have expressed interest
- All groups expressed concern discussion would take away hope and scare the patients

Focus Groups

- Patients and caregivers were concerned with logistics and how this would affect family during grieving time.
- Clinic staff and patients felt having a general campaign to bring awareness would be an important first step.
- Physicians and clinic staff reported training is necessary with discussion script and specific details on the procedures/logistics.
- Patients and caregivers felt physicians and consenters need to have specific training about sensitive communication and wait for patient cues.
Pathologist

- Pathology refers to existing imaging and Body Map (completed by thoracic MD) for tissue retrieval.
- Concerned about cost and time.
- Concerned about general limitations of funeral cosmesis as it affects tissue procurement.
LifePath Hospice

- Hospice staff very familiar with advanced directives and discussing end of life issues with patients.
- Hospice provides opportunities for patients and families to participate in other posthumous donation programs.
- LifePath Hospice expressed support of RTD.

Local Funeral Homes

- Concerned with additional fees incurred when repairing bodies after a full autopsy/donation procedure.
- Programs must ensure family not responsible for any fees associated with RTD.

LifeLink Tampa

- LifeLink Tampa does not accept donations from deceased with long-term illness or disease (exception: cornea)
- Tissues and organs donors between the age ranges of 15-55 (women) and 65 (men).
- LifeLink incurs all charges from donors including hospital bills and funeral home bills.
National Disease Research Interchange (NDRI)

- The NDRI conducts research after gaining consent from patients to obtain surgical samples from patients and post-mortem.
- NDRI collects tissue within 8 to 10 hours after death (this time constraint is specific to the level of tissue stability needed).
- NDRI sites have surgical team with training and protocols to extract the tissue based on the surgical weekly schedule.

Recommendations Based on Findings:

- Do use the word “donation”
- Do approach patients who have expressed interest in participating in research studies and are coping well with their diagnosis.
- Do engage family members in the consenting process.
- Do develop educational materials about RTD (e.g., brochures, flyers).
- Do give family members the final decision and authority to revoke consent.
Recommendations Based on Findings:

- Avoid the word “autopsy”
- Avoid approaching every patient; instead wait for cues.
- Avoid discussions about RTD during initial appointments.
- Avoid having other staff initiate discussions about RTD with patient, instead it should be the treating physician who initiates this discussion.
- A verbatim script may be necessary for physician comfort level and to ensure requests are uniform

Current Developments

- A brochure was developed
- Talking points were developed to help physicians delicately approach patients.
Next Steps

Long-Term Goal:

Develop an RTD program at Moffitt and collaborate with other Lung SPORES in both protocols and tissues in order to obtain a unique collection of specimens to further the research of lung cancer.

- **Develop a pilot study to recruit five patients with advanced stage lung cancer to determine the feasibility of establishing a rapid tissue donation program at Moffitt Cancer Center.**
REFERENCES

